The implementation of EHealth in dementia care

KNOWLEDGE VALORISATION

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The main aim of this thesis was to is to gain insight into the factors that influence the implementation of eHealth interventions for caregivers of people with dementia. In this valorisation paragraph, we describe how the obtained knowledge from our research can be put into practice for clinical and societal use.

Societal relevance

Approximately 9.1 million people are currently living with dementia in EU member states. The total number of people living with dementia in Europe has been predicted to rise by about 60%, and is expected to reach 14.3 million by the year 2040. The Council of the European Union has recognized that dementia is one of the major causes of disability and dependency among older adults, as well as its considerable impact on physical, psychological, social, and economic outcomes for people with dementia, their informal caregivers, and society at large. In particular, research has drawn attention to dementia care's reliance on informal care (also known as unpaid care or family care) and its effects on informal caregivers.

Recent research has shown that eHealth, can significantly improve outcomes for caregivers of people with dementia. In general, the advantages of eHealth interventions include easy personalisation, fast delivery, and real-time feedback. In the context of today's ageing population and society's increasing reliance on informal caregiving, eHealth is an especially suitable tool. In this regard, benefits include the potential of eHealth to widen service access to more remote areas, lower thresholds to participation, improve service efficiency, and reduce costs. eHealth interventions also offer dementia-specific advantages, as they can be personalised and adapted to the progressing stages of dementia, offer caregivers psychoeducation without requiring them to leave the person with dementia home alone, and provide support without facing the stigma often present with a dementia diagnosis.

Unfortunately, previous research has shown that only 3% of psychosocial interventions for caregivers of people with dementia are implemented into practice. This was confirmed to also be the case specifically for eHealth interventions for caregivers of people with dementia. The studies described in this thesis provide insight into the lessons that can be learned from previous successful and unsuccessful implementations of eHealth interventions to support caregivers of people with dementia. In addition, these studies describe lessons from the continued implementation of eHealth interventions for caregivers of people with dementia, providing relevant use cases and shedding light on the specific implementation context of the local municipality.

Target audience

The findings described in this thesis are relevant for caregivers of people with dementia, researchers, dementia health care professionals, health insurers, funders, and policy makers.

Insight into the factors that influence the implementation of eHealth interventions for caregivers of people with dementia can help increase the previously described low implementation rate in order to provide the intended benefits for caregivers of people with dementia. While often rewarding and enriching, the informal caregiving experience for a person with dementia has also been shown to have considerable negative effects on caregivers, such as chronic stress, caregiver overburdening, depression, anxiety, social isolation, financial burden, and disturbed sleep. Given eHealth's proven effects on caregiver self-efficacy and dementia caregiving knowledge, as well as the reduction of symptoms of depression and anxiety, the findings of this thesis are especially relevant for caregivers of people with dementia, as they stand to benefit the most from these interventions becoming sustainably available to them.

Next, this thesis described a number of important implications for the development and implementation of evidence-based eHealth interventions for caregivers of people with dementia, which are especially relevant to researchers in the field of eHealth (and dementia). These include the incorporation of checkpoints, innovation clusters, and flexible research designs into eHealth research.

Furthermore, dementia health care professionals will find this thesis' recommendations for organisational implementation relevant to them. In particular, the findings concerning the need to create self-efficacy and ownership, as well as the suggestions concerning continuous monitoring and feedback of the interventions within the health care organisations can be of added value in this setting.

Finally, health insurers, funders, and policy makers are included in the target audience of this thesis. This is because the included studies' insights concerning the most successful implementation trajectories and business models, protocols for optimal organisational implementation, perspectives on eHealth from a wide variety of intersectoral stakeholders, and the obtained process data can help inform a more efficient allocation of public money and health care resources.

Activities and products

As a result of the thorough implementation research of this thesis, the eHealth interventions Partner in Balance and Myinlife were able to evolve from research projects to sustainable products. These research activities included stakeholder interviews, business modelling,

and context mapping. This research has resulted in the sustainable scaling-up of these interventions, and provided content for much-needed implementation protocols, which will now be a part of Myinlife and Partner in Balance's standard implementation packages for both municipalities and health care organisations.

The findings from this research were presented at several international scientific conferences and symposia, as well as at various dementia caregiver meetings, client panels, and Alzheimer Cafés. Moreover this project has been featured through several media channels, such as on UK Health Radio's dementia show 'The D-Word', the Alzheimer Europe twitter account, the Alzheimer Nederland website (www.dementie.nl) and the Belgian young onset dementia website (www.jongdementie.nl), RTZ Z television show '*De Barometer'*, and as an enduring part of the euPrevent Senior Friendly Communities project.

Innovation and implementation

This project's first study, the systematic review, indicated that there was an important knowledge gap concerning the implementation of eHealth interventions for caregivers of people with dementia. This thesis made use of an innovative combination of intersectoral frameworks (from implementation science, psychological interventions development, and business) and methods (systematic literature review, qualitative surveys, semi-structured qualitative interviews, inductive and deductive thematic analysis, stakeholder analysis, multiple case study analysis, and business model analysis) to help fill this gap with insights on the organisational and contextual implementation determinants of eHealth interventions for caregivers of people with dementia.

This project resulted in both the practical implementation of two eHealth interventions for caregivers of people with dementia (Partner in Balance and Myinlife) on a larger scale, as well as more generalisable eHealth implementation insights, which are useful for a variety of dementia stakeholders. The process findings from this implementation research are also proving valuable in providing more context to research funding applications for Partner in Balance, and constitute a more solid evidence base for these applications. Here, we would like to reiterate the importance of operationalising the implementation of these implementation lessons. Findings on the effectiveness of the implementation strategies and the monitoring of the interventions should be discussed further by stakeholders, for example in focus groups.